



Giving a voice to Alzheimer's disease patients

Study design and experiences of a novice qualitative researcher

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Introduction

State of the art

- Experience of **Meaning in Life (MiL)**¹
 - My life = coherent, valuable, purposeful
 - 'I understand who I am, what the world is like, and how I fit in it'
 - Important for well-being and positive functioning
- MiL concept presupposes many higher **cognitive abilities**
- People with **dementia** suffer loss of cognitive abilities e.g., reflecting on past and future, abstract reasoning, verbal skills

Questions

- Do people with dementia lose their ability to experience MiL?
- Or is our understanding of the MiL concept too limited?



- Need for **enrichment** of overly cognitive framework in MiL research
- Need for attention to **lived experience** of dementia patients themselves

Method:

- Open, in-depth interviews on three occasions over two years
- Shift to observational method of shadowing when interviewing becomes difficult; meaning through the whole physical being, i.e., verbal as well as bodily expressions



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Design

- **Qualitative study** embedded in longitudinal mixed-method project
- Participants: Alzheimer's disease (AD) patients in Flemish residential care settings
- **Reflective lifeworld approach** based on phenomenology and hermeneutics²
 - The phenomenon of the experience of MiL by AD patients
 - Openness: sensitiveness to the unexpected; a wish to understand something in a new way
 - Bridling: restraining the pre-understanding; "not making definite what is indefinite"

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Reflections

Challenges

- Dealing with criticism and doubts about subjectivity in data collection and analysis, and validity of findings
- Shift in mindset of the researcher: Positivistic, analytic → pragmatic, holistic
- Need for constant reflection toward the own natural mindset, and for deep commitment and patience
- AD patients: probable difficulties in maintaining focus and coherence; possibly less articulate during interviews
- Is it possible to truly grasp and describe the lived experience?

Opportunities and assets

- Giving attention to the lived experience of a vulnerable group too often excluded
- New insights and perspectives through open, flexible, sensitive attitude and bridling of researcher's understanding
- Gaining information not obtainable through quantitative methods
- Supported by philosophical underpinnings

References

- ¹ Steger, M. F. (2009). Meaning in life. In S. J. Lopez & C. R. Snyder (Eds.), *Oxford handbook of positive psychology* (pp. 679-687). New York, NY: Oxford University Press.
- ² Dahlberg, K., Dahlberg, H., & Nyström, M. (2008). *Reflective lifeworld research* (2nd Ed.): Studentlitteratur, Lund.

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